



NPCR Education and Training Series (NETS)

Module 2: Abstracting for the Beginner

Part 1: Cancer as a Reportable Disease

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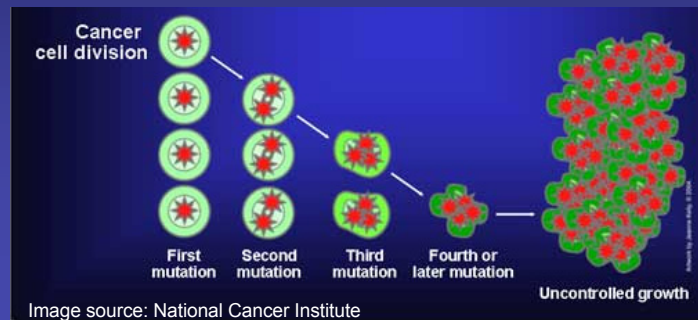
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National Program of Cancer Registries
Atlanta, Georgia
www.cdc.gov/cancer/npcr



This presentation was developed to introduce new cancer reporters to the functions of a central cancer registry (CCR) and why reporting of cancer is required in every state and territory in the United States. You will learn a little about cancer itself, what your responsibilities are as a reporter are, and how to complete a cancer abstract.

What Is Cancer?

- ◆ Caused by a mutation in DNA
- ◆ Abnormal cells:
 - Divide uncontrollably
 - Destroy normal body tissue
 - Can spread throughout the body



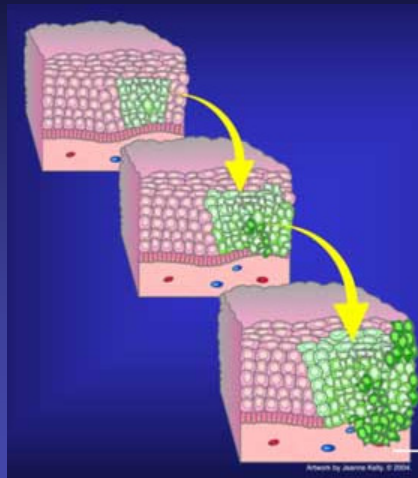
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Cancer is caused by a series of mutations in a person's DNA. DNA is the set of instructions telling your cells how to grow and divide. When a mutation occurs in a cell, the cell becomes abnormal and begins to grow and divide at abnormal rates. Cancer cells eventually destroy normal body tissue and begin to spread throughout the body.

How Does Cancer Grow?

- ◆ Cancer cells grow at an abnormal rate.
- ◆ Accumulation of cells forms a tumor.
- ◆ Tumors develop a blood supply.
- ◆ The cancer grows and spreads.

Image source: National Cancer Institute



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Cancer cells that grow at an abnormal rate begin to accumulate. Eventually, a tumor or mass develops. Tumors remain small until they develop their own blood supply, which allows them to grow **larger**. **As they obtain oxygen and nutrients from this increased blood supply, they** start to spread. A cancer can spread in three ways. The cancer can grow directly into nearby tissue or organs, **called** “local spread.” The cancer can spread through the bloodstream and form a secondary cancer or “metastasis” **in a distant site**. The third way a cancer spreads is through the lymphatic system. The cancer travels through the circulating lymph until it gets into the small channels in the lymph node and begins to grow.

The diagnosis and treatment of cancer is an enormous financial burden on the American economy. Surveillance or monitoring of the cancer burden in the U.S. population is an important function of the public health services at the national and state levels.

Why Report a Cancer? ₁

- ◆ Cancer diagnoses are reported in every state to a central cancer registry.
- ◆ Reporting cancer diagnoses is important to the gathering of statistical information on cancer incidence.
- ◆ Reporting cancer diagnoses assists cancer control and hopefully one day will lead to a cure for cancer.

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As noted, every state has laws that mandate the reporting of newly diagnosed cancers. Although each state has different laws and regulations regarding their cancer control activities, all report using the same coding systems so the data can be compared on national and international levels. The cancer cases are reported to a central or regional state cancer registry, where the data are compiled and checked and then forwarded to other national agencies to be included in national cancer statistics. The reporting of cancer diagnosis is important to the development of statistical information that promotes research in the areas of cancer prevention, diagnosis, treatment, and survival. The efforts of all cancer registries across the country have assisted in cancer control efforts and hopefully some day will lead to finding a cure for cancer.

Why Report a Cancer? ₂

- ◆ **National Cancer Act of 1971 mandated collection, analysis, diagnosis, and treatment of cancer.**
- ◆ **Cancer Registries Amendment Act of 1992 expanded collection of cancer data nationwide:**
 - **Established National Program of Cancer Registries.**

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Cancer data has been collected systematically for more than 50 years. The importance of collecting and reporting cancer data was further emphasized in 1971, when the “War on Cancer” began and established federal collection of cancer data by the National Cancer Institute.

In response to the needs of the nation to better monitor cancer incidence and trends and cancer control efforts, Congress enacted the Cancer Registries Amendment Act of 1992, which expanded cancer reporting to all states and territories. That law also established the National Program of Cancer Registries (NPCR). The Centers for Disease Control and Prevention (CDC) was charged with enhancing central **cancer** registries where they already existed and developing central **cancer** registries where they did not exist but were needed. Through this legislation, NPCR assists in the efforts to meet requirements for completeness, timeliness, and quality control of cancer data collected. They also provide education and training to data collectors in your state.

Why Report a Cancer? ₃

- ◆ Reporting cancer diagnoses is required by law in every state
- ◆ Requirements defined within each state
- ◆ Uses:
 - Inform health professionals of cancer risks
 - Focus cancer control activities in the state and nationally
 - Monitor the occurrence of cancer
 - Aid in research
 - Promote education, prevention, and early detection

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Every state has legislation that requires all entities that diagnose or treat cancer to report the cases to the state central cancer registry. The collection and study of cancer cases assists in educating health professionals on the risks of certain cancers. This risk may be specific to a certain population or a specific region of the state. Analysis of **the number of cancer cases** and trends allows the state to focus on cancer control activities pertinent to its population. The monitoring of cancer occurrences, known as incidence, allows proper focus on research and education, prevention and early detection measures, as well as better allocation of public health resources.

Why Report a Cancer? ₄

- ◆ **Cancer control efforts measure:**
 - **Benefit of early diagnosis/detection**
 - **Diagnostic imaging**
 - **Prognostic tumor markers**
 - **Use of specific treatment modalities**
 - **Improvement of treatment modalities**
 - **Research**
 - **Prevention**
 - **Survival**
 - **Quality of life**

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We can measure the success of cancer control in a population by looking at the benefits of early detection or diagnosis, diagnostic imaging, use of prognostic tumor markers, use of specific treatment modalities, improving treatment modalities, research, prevention, survival and quality of life.

We will look at each of these individually and how they apply to the completion of an cancer abstract.

Why Report a Cancer? ₅

◆ Benefits of early diagnosis/detection and diagnostic imaging:

- Screening mammography
- Colonoscopy
- Prostate-specific antigen (PSA)
- Pap smear
- Colposcopy

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If a cancer is found early, it is easier and **usually** less expensive to treat. Many states provide early detection services to their residents.

The benefit of early detection or diagnosis can be measured by capturing in text and codes the procedures and laboratory work the patient had performed when the cancer diagnosis was determined.

Examples include:

- **T**he colonoscopy the patient had performed when he/she presented with rectal bleeding.
- **T**he screening mammogram the breast cancer patient had that noted the 2cm mass within the upper outer quadrant of the right breast.
- **T**he elevated prostate-specific antigen level the prostate cancer patient had prior to his biopsy.
- **T**he abnormal Pap smear the cervical cancer patient had, which led to her colposcopy that detected the cancer.

All of these procedures or laboratory values should be recorded on the patient's cancer abstract to capture a true measure of the importance of early diagnosis or detection of cancer.

Why Report a Cancer? ₆

◆ Use of specific treatment modalities

- Surgery
- Chemotherapy
- Radiation therapy
- Hormonal therapy
- Hematologic transplant/endocrine procedures
- Immunotherapy
- Other cancer-related therapies

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Measuring the effectiveness of specific treatment modalities is one of the most valuable outcomes of collecting data about them. Documentation of the various treatments used to control cancer is pertinent to determining the success of cancer treatment. Often, combinations of therapy are used. It is important to track which combinations are most effective in the treatment of specific cancers. This is done by collecting detailed treatment information on each cancer case in an abstract. Researchers can use the information obtained to determine whether one type of treatment is more effective than another type.

Treatment modalities can also be enhanced and improved through collection of specific data. This data collection can assist physicians in providing better care to patients. An example is the use of medications to counteract the effects of certain treatment modalities, thereby affording the patient better quality of life.

Why Report a Cancer? 7

◆ Prognostic tumor markers

- Carcinoembryonic antigen (CEA)
- Prostate-specific antigen (PSA)
- Estrogen receptor assay (ERA)
- Progesterone receptor assay (PRA)
- Alpha feta protein (AFP)
- Lactate dehydrogenase (LDH)
- Cancer antigen 125 (CA-125)
- Human chorionic gonadotropin (HCG)

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Prognostic tumor markers can be of great value to clinicians. Although tumor markers are not yet measures for defining treatment in many instances, they are useful in measuring how a cancer is responding to treatment. One cancer site in which tumor markers are used to decide treatment is breast cancer. The estrogen and progesterone values are reported to the clinician from the laboratory, and hormonal therapy is administered accordingly. Many state cancer registries collect these tumor markers on the cancer abstract as site-specific factors.

Tumor markers have also assisted in the early detection of cancers. This is especially true of the prostate-specific antigen (PSA) for prostate cancer diagnosis.

Why Report a Cancer? ₈

◆ Cancer Research

- Clinical trials
- Cooperative or intergroup clinical trials



Image source: National Cancer Institute



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Many central cancer registries (**CCRs**) participate in cancer research. The CCR may require rapid reporting to identify cases for research. Cancer research can be done in collaboration with other organizations. Clinical research is a valuable resource in cancer control.

A clinical trial is a scientific study that evaluates investigational medications, treatments, and diagnostic and preventative techniques or devices.

Why Report a Cancer? 9

◆ Prevention

- Education
- Screening
- Population
- Race
- Gender

Image source: National Cancer Institute



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There are **three** types of cancer prevention efforts:

- Primary prevention involves modification of behavioral and environmental factors that may cause cancer to prevent its onset. Examples include immunization and public education.
- Secondary prevention are activities focused on early case finding of asymptomatic disease that occurs commonly and has significant risk for negative outcome without treatment. Screening tests are examples of secondary prevention activities.
- The third method of prevention, or tertiary prevention, includes activities that involve the care of established disease, with attempts made to restore to highest function, minimize the negative effects of disease, and prevent disease-related complications. An example is evidence-based treatments.

The most effective way to enhance prevention efforts is through education and screenings. Recording specific information on a cancer abstract assists in **identifying specific populations at risk for developing a certain type of cancer so that** appropriate education can be provided to **that** group of people. This can be based on specific populations, races, or a specific gender. For instance, we know through cancer data collection that African-American men are more susceptible to prostate carcinoma than white men. Other educational forums developed by state health departments include stop smoking campaigns, breast self-exam education, **colon cancer screening**, and efforts to increase awareness of cervical cancer.

Why Report a Cancer? 10

◆ Survival and quality of life

- Disease-free survival
- Survival of specific populations
- Survival of specific age groups
- Survival of site-specific/treatment modality
- Measures of symptom-free survival

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The measurement of survival is at the core of the study of medical treatment. The disease-free interval of a patient can be measured to determine the success of the treatment given. Symptom-free survival can measure the quality of life in comparison to the treatment being given to control the cancer. These measurements are equally important in the collection of cancer data. Although patients may still live with disease (cancer), their quality of life may be substantially affected by the disease. Epidemiologists look at various survival rates to see if there are differences by race, sex, or age. Cancer control efforts can be successful only if we document the specifics within the abstract necessary to differentiate one population, for example a sex or race, from another. Coding accuracy is extremely important in cancer documentation.

The American College of Surgeons, Commission on Cancer requires their approved programs to collect survival data. However, not all central cancer registries (CCRs) collect this data. CCRs supported by the National Program of Cancer Registries are not required to collect this information, but CCRs supported by the Surveillance, Epidemiology, and End Results program are required to collect it.

Why Report a Cancer? 11

◆ What is a cancer registry?

- A database where the collection of a uniform set of data items is recorded on all reportable cancer cases.

◆ What is cancer registration?

- A fundamental method whereby information is systemically collected about the occurrence of cancer.

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Cancer registries came into existence in the United States in 1923. The purpose of the cancer registry is to track the etiology, management, and survival of cancer patients. The completeness, timeliness, and quality of cancer reporting is important to monitoring of cancer incidence and cancer control efforts. Every cancer must be identified and reported. Each body part has its own specific code. These codes are part of national and international data standards. Cancer data collectors have multiple manuals to which they must refer to report cancer incidence accurately.

Why Report a Cancer? ¹²

◆ The role of central cancer registries

- Population-based registry collects data on all cancer patients within a particular region
- Information on trends
- Occurrence
- Outcomes

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The role of the central cancer registry (**CCR**) is to collect data on all cancer patients within a defined geographic area, such as a state or county. This includes patients who are diagnosed within the region but who may receive their treatment outside of the area. A **CCR** also records cancers diagnosed only on a death certificate or **in an** autopsy report. **CCRs** are interested in information on trends in the occurrence of various forms of cancer. In addition, there is great interest in changes in treatment modalities over time and how this affects patient survival (patient outcomes) and the epidemiology of cancer. For instance, we know smokers often develop lung cancer. Through the use of cancer data collection over the years, epidemiologists recognized a higher occurrence of lung cancer in smokers. Education **programs** on the effects of smoking have **been** implemented **at state and** national levels, and some states have very strict cancer control policies to counter the effects of secondhand smoke. This action occurred as a direct result of cancer reporting.

Why Report a Cancer? ¹³

◆ Requirements for reporting cancer

- Cancer registry software
- Case ascertainment (case finding)
- Abstract completion
- Transmission of data

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To meet the requirements of your central cancer registry (**CCR**) and report the cancer cases from your facility, you need:

- Software—either provided by the state or licensed by your facility.
- Rules for which cases are reportable to the state—your **CCR** will provide you with these.
- Instructions for what data is to be reported, **including** how to complete the **data** fields on the abstract. The format of the abstract is standardized in each state and will be discussed in future slides.
- After the abstract is completed, the data must be transmitted or submitted to the CCR.

Why Report a Cancer? 14

◆ Software

- ABSTRACT Plus

www.cdc.gov/cancer/npcr/tools/registryplus/ap.htm

- Compatibility

- Technical assistance

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Cancer registry software is an extremely important component of abstracting. The software used by many central cancer registries for their non-registry reporting facilities is ABSTRACT Plus. Later in this presentation, we will discuss and show documents of ABSTRACT Plus.

It is important to understand what is needed to support your registry software. Case ascertainment or case finding can be done with the help of other software available within your facility. If that software and the abstracting software are compatible, processes for identifying new cases can be streamlined to save time and money. Occasionally, technical assistance is may be needed. It is a good idea to have an information technology person at your facility become familiar with your registry software so updates or upgrades can be installed without issue when needed.

Why Report a Cancer? ¹⁵

- ◆ Case Ascertainment (Case finding)
 - What is reportable?
 - ◆ Case eligibility criteria
 - ◆ Reportable list – ICD-0 and state central cancer registry
 - ◆ Case finding sources and procedures
 - ◆ Suspense file
 - ◆ Filing systems

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It is important to develop processes within your facility to determine which cases are reportable to the **central cancer registry**. The standard references for determining reportable cases are the **most recent edition of the *International Classification of Diseases for Oncology*** and your state's reportable case list. Regardless of the mechanism of identification, case finding sources and procedures have to be developed into policy and procedures for your facility. When case finding procedures are completed, you will have a list of cases you know must be reported to the state. **This is** called a "suspense file."

The filing systems used can be extremely important in the effectiveness and timeliness of abstracting procedures. The more organized you are, the more efficient and timely you will be in reporting to the state.

Why Report a Cancer? 16

◆ Documentation required:

- Patient information
- Cancer identification
- Extent of disease
- Treatment information

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The documentation collected by a **central cancer registry** abstract must be standardized to ensure quality of the data. The documentation is comprised of the following sections, referred to as an “abstract”:

- **Patient information:** This section of the abstract includes demographic information—patient name, address, and so forth.
- **Cancer identification:** This section includes the information pertinent to the cancer diagnosis.
- **Extent of disease:** This section documents how far the cancer has spread. It requires the use of coding manuals to complete. The coding is specific to each cancer site.
- **First course treatment information:** This section contains the treatment given to the patient specific to the cancer diagnosed. It includes surgical procedures, chemotherapy, radiation therapy, hormonal therapy, and, in some cases, the decision to watch and wait.

All of these components of the abstract will be discussed in further detail when we discuss how to complete an abstract.

Why Report a Cancer? 17

◆ Transmission and security of data

- Timely
- Confidentiality ensured
- Controlled access
- Security
- Backup of data

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When the abstract is complete, the data must be transmitted to the central cancer registry (CCR). This transmission must occur within the timeframe set forth by the CCR, and the confidentiality of the patient's record must be ensured. Data security is extremely important. Measures should be taken to ensure the data is stored so that there is controlled access. Computerized data should be encrypted to ensure confidentiality. This is usually a function of the registry software.

It is also important to have a regularly scheduled routine backup of data and testing of the backup copies to be sure you have a reliable backup system.

What Central Cancer Registries Do ₁

- ◆ Timeline of abstraction
- ◆ Edits
- ◆ Facility data to CCR
- ◆ Merging of abstracts
- ◆ Collection of missing data
- ◆ CCR data to national agencies
- ◆ Dissemination of data to other cancer agencies
- ◆ Quality control and education

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When discussing **data** reporting, we need to **include**:

- Timeline for abstracting
- Edits
- The transmission of facility data to the central cancer registry (**CCR**)
- The merging of **information from multiple** abstracts **by** the CCR
- The collection of **any** missing data after records are merged
- The transmission of data from the CCR to the national **agencies**
- The dissemination of cancer data to other agencies, such as the American Cancer Society

CCRs may provide abstractors to assist with timely data collection. They may **also** perform **data completeness and quality studies or** audits on the data at your facility. The audits allow **CCR** personnel to know where further education is needed and are a great mechanism for quality control.

What Central Cancer Registries Do ₂

◆ Timeline of abstraction

- Facilities are usually required to report cases to the CCR within 6 months of diagnosis or date of admission.
- CCRs must report 90% of expected cases to NPCR within 12 months of the close of the diagnosis year.

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It is important that reporters understand the expectations of central cancer registries (CCRs). The timelines for reporting to the CCR may vary from monthly transmission of data to quarterly transmissions. Regardless of the frequency of transmission, reporting facilities are usually expected to transmit cases to the CCR within six months of the diagnosis or date of admission. This allows the CCR to conduct their quality assurance and consolidation activities in time to meet their national reporting requirements. NPCR requires their CCR participants to report 90% of their expected cases within 12 months of the end of the diagnosis year.

What Central Cancer Registries Do ₃

- ◆ Data transmission from facility to the CCR should occur at regular intervals agreed upon by the facility and their CCR.
- ◆ Form of transmission should be clearly stated and written into a policy and procedure for that facility.

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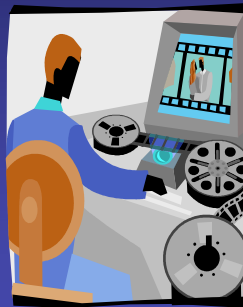


Continuous case abstracting and submission of cases throughout the year is the best practice, as opposed to trying to abstract the entire year's cases in a short time and sending them in to the central cancer registry (CCR) in one batch. The CCR will establish a reporting schedule for each facility and determine how the cases should be transmitted, either electronically or on paper. This agreed-on schedule and method of transmission should be recorded in the facility's policy and procedures.

What Central Cancer Registries Do ⁴

◆ CCR edits

- Visual editing
- Software editing
- Discrepancies
- Reporting to facility



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The central cancer registry (CCR) will perform visual and software-specific editing on all cancer data abstracts submitted. Visual editing compares text documentation to codes, and software editing checks to make sure codes are in accepted ranges and appropriate to data recorded in other related fields. Any discrepancies noted within the visual or software editing need to be validated or corrected by the reporter and resubmitted. The reporter needs to be clear on how and when these reports will be provided to them. The CCR can provide their policy and procedures on reporting edit issues. The timeline for correction and resubmission of discrepancies to the CCR should be understood. The timelines may vary by state.

What Central Cancer Registries Do ⁵

◆ Merging of Abstracts

- Records received at the CCR are checked for duplicate patient reports.
- Multiple reports for same patient are merged to capture most complete demographic data.
- Multiple reports for same patient are checked for new tumors (same vs. new primary).
- Multiple reports for the same tumor are merged to capture most complete diagnostic, staging, and treatment data.

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Often cancer patients **receive** treatment at more than one facility, **or are** diagnosed at one facility and treated at another. When this occurs, duplicate cases are **submitted to** the **central cancer registry (CCR)**.

The CCR performs case consolidation by merging **the information** on reports from **these** multiple sources **into one report** after confirming the reports are truly the same patient with the same cancer or one patient with multiple cancers.

A single record is created if the same cancer is reported by more than one source. Separate tumor records are created **for the patient** if the reports are for multiple cancers in the same patient.

The reason for merging the patient reports is to make sure a cancer is reported only once, regardless of how many facilities the patient goes to. Over-reporting of cancer incidence can occur by inadvertently retaining duplicate cases in the CCR database.

What Central Cancer Registries Do ₆

◆ Collection of missing data

- The abstract is edited and reviewed at the CCR for completeness.



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In addition to edits, the **central cancer registry** will review the abstract for completeness against the regional, state, and national guidelines for cancer reporting. It is important that the reporter know and understand what is expected to be reported in his or her region and state as well as at the national level. When a data element or treatment modality is unknown, it is important for the reporter to document that the information is not available—in other words, unknown—rather than leave the field blank. We will talk more about this when we discuss completing an abstract.

What Central Cancer Registries Do 7

- ◆ Data transmission from the CCR to the national agencies can only occur after all edits have been resolved, and the abstract is complete with all coding elements and treatment modalities.

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For data to be sent from the central cancer registry (CCR) to national agencies, the CCR staff must ensure the abstract is as complete as possible, with all discrepancies resolved and all appropriate treatment modalities recorded. After this has occurred, the abstract can be forwarded for use at the national level. When the data leaves the CCR, all patient identifiers are removed.

This is a very important step in cancer reporting. These data produce our national cancer statistics, generate future cancer research, and support cancer surveillance funding and changes to treatment modalities. It is vital that the cancer reporter know and understand his or her role in cancer control. State, national, and international cancer data are only as accurate as the reporters who collect the data and the quality control experts who review the submitted data.

What Central Cancer Registries Do ₈

- ◆ Dissemination of cancer data to other agencies
 - Data is shared with other administrative agencies, such as the parent agency, CDC, the North American Association of Central Cancer Registries (NAACCR), and the World Health Organization (WHO).
 - The American Cancer Society (ACS) also uses the statistical data collected to report trends in cancer incidence.

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The **data collected at central cancer registries** are disseminated in an effort to improve the success of cancer control efforts. Statistics are reported and recorded annually in an effort to educate not only health care providers, but more importantly, the general public.

Why Report a Cancer? 18

◆ Summary

- The CCR is a repository of data that includes all cancers diagnosed in a geographic area.
- The data includes information about the patient and the extent of the disease at the time of diagnosis, as well as the treatment provided to the patient.

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In summary, central cancer registries (CCRs) have an important function in monitoring the public's health in regard to cancer. The amount of data collected by a CCR contributes to the body of knowledge about cancer. The collected information is used for many purposes at the state and national level.

Why Report a Cancer? 19

◆ Summary (continued)

- The registration of these cancers is managed by timely reporting through registry software.
- The completion of an “abstract” on each cancer diagnosis is just the first step in the complicated process of cancer reporting.

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Health care facilities are required to report cancer to the central cancer registry (CCR) **usually** through specialized software. Collection of the data on a cancer abstract is just the first step in the process of creating a database for research and surveillance of cancer nationwide. When the CCR receives cases from its reporting facilities, the CCR makes sure the data are complete and accurate before making them available to researchers and the public.